

Lesson 11

Public Health Surveillance and the Law

Instructor's Guide Form

Lesson Title: Public health surveillance and the law

Lesson Goal: For learners to be able to discuss the basic issues regarding public health surveillance and the law.

Learning Objectives: By the end of this lesson, the learner will be able to:

- 1) describe the connection between public health surveillance and the law
- 2) describe the main issues in the history of surveillance and the law
- 3) describe the key current legal issues
- 4) explain procedures to consider when setting up and running surveillance programs

Equipment and Materials Needed:

- Overhead projector
- Transparencies #11.1 - #11.12

Time Required: 60 minutes

Synopsis of Lesson: This lesson describes the connection between public health surveillance and the law in the U.S. It provides a summary of the key legal issues which impact surveillance and suggestions to be considered when designing and operating a surveillance program.

Lesson 11

Public Health Surveillance and the Law

Instructor's Guide Form (continued)

Adult EducationApplication: During an instructional process, adults learn best from interacting with information in a manner that mirrors their work setting. One technique that can encourage adult learning is the use of role playing. In this chapter on the law, the use of a role playing exercise could add a lot of interaction with the material. The role plays can take some time to set up. The key to their success is providing the characters in the role play with a clear, precise definition of their roles. One way to introduce greater clarity to the role playing exercise is to prescript the parts. A prescript includes a brief description of the characters' purpose in the exercise, the key points that the characters need to make, and the characters' nonnegotiable points. Each character should be given a prescript and some time to rehearse. The instructor sets up the premise of the role play, the ground rules to follow, and the role of the observers during the exercise. The role of the instructor is to observe the process, intervene only when necessary, and process the activity with both the characters and observers at the end of the exercise.

Lesson 11

Public Health Surveillance and the Law

Topical Outline

- I. Relationship between public health surveillance and the law**
 - A. Working definition of the law
 - B. Legal rights
 - C. Police powers of a state
 - D. Surveillance must be considered under umbrella of "accepted practice" and "the law"

- II. History of surveillance and the law**
 - A. Prior to 1900
 - B. Surveillance from 1900-1930
 - C. Gradual growth in mandated surveillance (1940-1970)

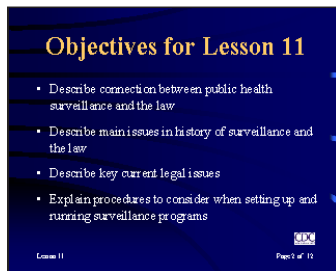
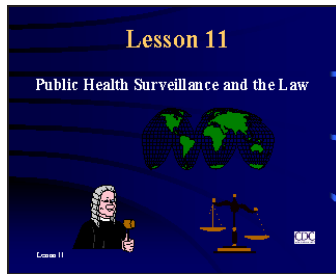
- III. Current legal issues (1980 to the present)**
 - A. Effects of HIV/AIDS
 - B. Key legal issues that impact surveillance in the 1990s
 - C. Personal privacy
 - D. Right of access
 - E. Product liability
 - F. Litigation demands

- IV. Conclusion**
 - A. Considerations for setting up and running surveillance programs
 - B. Surveillance as a bridge

Lesson 11

Public Health Surveillance and the Law

Content Outline



Lesson Objectives:

- Describe the connection between public health surveillance and the law
 - Describe the main issues in the history of surveillance and the law
 - Describe the key current legal issues
 - Explain procedures to consider when setting up and running surveillance programs
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I. Relationship between public health surveillance and the law

A. Working definition of the law

1. "the sum or set or conglomerate of all of the laws in all of the jurisdictions: the constitutions, the statutes, and the regulations that interpret them, the traditional principles known as common law, and the judicial opinions that apply and interpret all these legal rules and principles" (Wing)
2. the law is also the legal profession
3. the law is also the legal process
4. the law is what it is interpreted to be
5. basic function of the law is to establish legal rights

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6. basic purpose of the legal system is to define and enforce those rights

Legal Rights

- concept covers the protection of carefully specified interests against the effects of other carefully specified interests
- some rights are protected, not by statute or regulation, but by an understanding and application of the prevailing ethics in the area
- ethics are regulated through whatever sanctions are imposed against censured behavior by peers or colleagues

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B. Legal rights

1. the relationships that establish privileges and responsibilities among those governed by the legal system
2. concept does not purport to cover freedoms or interests given unconditional, global protection
3. concept covers the protection of carefully specified interests against the effects of other carefully specified interests
4. some rights are protected, not by statute or regulation, but by an understanding and application of the prevailing ethics in an area
5. ethics are regulated through whatever sanctions are imposed against censured behavior by peers or colleagues

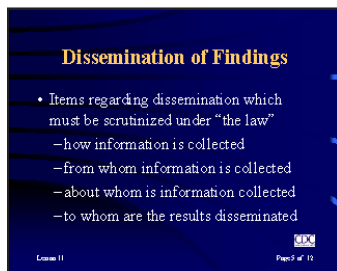
Police Powers of a State

- the powers inherent in the state to prescribe within the limits of state and federal constitutions, reasonable laws necessary to preserve the public order, health safety, welfare, and morals
- covers public health surveillance

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C. Police powers of a state

1. the powers inherent in the state to prescribe within the limits of state and federal constitutions, reasonable laws necessary to preserve the public order, health, safety, welfare, and morals
2. describes a sweeping scope of authority



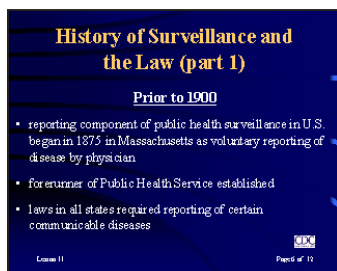
3. covers anything that would be dealt with under the heading of "public health surveillance"

D. Surveillance must be considered under umbrella of "accepted practice" and "the law"

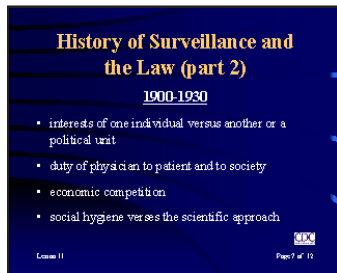
1. "timely dissemination of findings" is included in the definition of surveillance
2. items regarding dissemination include:
 - a. how information is collected
 - b. from whom information is collected
 - c. about whom information is collected
 - d. to whom the results are disseminated

II. History of surveillance and the law

A. Prior to 1900



1. reporting component of public health surveillance began in U.S. in 1874
 - a. by the State Board of Health in Massachusetts
 - b. began the first statewide voluntary plan for weekly reporting of prevalent diseases by physicians
2. the turn of the century
 - a. forerunner of Public Health Service had been established
 - b. laws in all states required that certain communicable diseases be reported to local authorities



B. Surveillance from 1900-1930

1. as surveillance grew, conflicts developed when the interests of one individual conflicted with those of another individual or political unit
2. most of the debate took place because of the problem the U.S. was experiencing with sexually transmitted diseases (U.S. troops in WWI)
3. issues of this time
 - a. the moral dilemma created by not reaching consensus on the purpose of information obtained through surveillance whether to direct control efforts
 - 1) toward sexual behavior of the individual or
 - 2) toward the disease agents
 - b. the debate surrounding the duty of the physician to his / her patient, and to society
 - c. the disagreement about whether government provision of health services comprised unfair competition to the private practitioner
4. social hygiene versus the scientific approach
 - a. example of syphilis
 - 1) just beginning to appreciate the fact that many “innocent victims” were getting syphilis
 - 2) prevailing wisdom of earlier years of “reaping what one sowed” was no longer adequate
 - 3) medical and public health officials had the most difficulty reconciling how to direct their efforts to deal with the growing problem

- 4) both surveillance and treatment efforts could be directed in one of two ways
 - a) directed toward people, a focus on behavior modification through education as a control strategy
 - b) directed toward the disease vector, a focus on the organism that caused the disease and how to eliminate it from individuals and society at large
- 5) neither approach was ever agreed to be ideal
- 6) two in combination have still not proved totally effective
- b. tension of “moral” versus “scientific” dilemma continues today
 - 1) HIV/AIDS
 - 2) reemergence of multi-drug-resistant strains of tuberculosis

5. duty of physicians

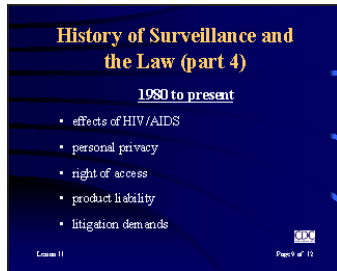
- a. factor of Hippocratic oath
- b. conflict arose during syphilis epidemic
 - 1) physicians did not wish to breach the confidence relied on by their patients by reporting certain cases
 - 2) if they did not report the occurrence of syphilis, they were tacitly participating in the continued transmission of the disease to “innocent victims”
- c. issue concerns the primary responsibility to an individual or society
- d. issue has not been resolved

- e. issue constitutes an important component of the success or failure of present-day surveillance efforts
6. economic considerations
- a. example: early syphilis epidemic
 - 1) issue of having physicians report all cases of STD's and to establish public health clinics to provide prompt treatment and education to patients
 - 2) other issue of the need for public health officials to protect the financial interests of physicians by not infringing on their turf and removing paying customers to free or financially subsidized facilities
 - 3) dilemma guaranteed under-reporting of cases
 - a) selective reporting of cases representing patients who could not pay
 - b) withholding of reports of cases representing patients who could pay
 - 4) context of HIV/AIDS
 - a) physicians might choose not to report HIV positivity for fear their patients might be discriminated against in a work or social setting
 - b) problems with insurance coverage might also lead to such under-reporting



C. Gradual growth in mandated surveillance (1940-1979)

1. states added many diseases to their mandatory reporting lists
2. surveillance and reporting efforts were broadened during this period through state regulation or directives from the state health commissioners
3. surveillance and reporting to agencies in the federal government were, and continue to be, voluntary
4. resulting discrepancy in data obtained (between states and federal government) leads to problems in analysis and interpretation
 - a. professional organizations' role is instrumental in setting up a patchwork system to coordinate and improve the quality and completeness of surveillance data
 - b. examples: Association of State and Territorial Health Officers (ASTHO), Council of State and Territorial Epidemiologists (CSTE)
5. major factor in development of surveillance planning and implementation during this period
 - a. Federal Protection for Human Subjects Regulations (1976)
 - b. one regulation states the requirements that informed consent be obtained from any person who is asked to participate in a medical research project
 - c. regulation covers compensation for persons injured during the course of the project
 - d. regulation confirms ethics of the research being conducted



III. Current legal issues (1980 to the present)

A. Effects of HIV/AIDS

1. biomedical research and surveillance activities of the 1980s were greatly affected
2. issues of early 20th century reemerged
 - a. do we want to treat persons for the disease or modify their behavior in control and prevention efforts?
 - b. is the physician's primary duty to protect a patient's privacy or to the greater good of society?
 - c. is the public health machine treading on the physician's turf by advertising and providing medical treatment more inexpensively than the physician can?
3. public health action cannot wait until consensus is reached before constructing and applying interventions

B. Key legal issues that impact surveillance in the 1990s

1. personal privacy
2. right of access
3. product liability
4. litigation demands

C. Personal privacy

1. right of privacy protected under the law is a vast gray area

2. U.S. Constitution does not specify a right to privacy
3. particular circumstances regarding privacy are addressed in the Bill of Rights (protection from “search and seizure”)
4. hotly debated issue in the early 20th century
 - a. example of syphilis and other STDs
 - b. concept of medical secret
 - c. many physicians opted to remain within the accepted double standard of behavior of the day
5. public health officials continue to struggle with rights of individual versus the good of society
6. Griswold vs. Connecticut (1965)
 - a. resulted from arrest of the director of the Planned Parenthood League of CT on the grounds that she had provided information, instruction, and medical advice about contraception to married people
 - b. in CT at that time, use of contraceptives was punishable by law
 - c. U.S. Supreme Court declared the CT law to be unconstitutional and reversed the criminal convictions
 - d. “various guarantees create zones of privacy” (Justice Douglas)
 - e. referred to this constitutionally recognized right of the individual to privacy in certain contexts as a “fundamental interest”
7. Roe v. Wade (1973)
 - a. a single woman challenged the constitutionality of a Texas law forbidding abortion (except when the pregnant woman’s life was in jeopardy)

- b. she claimed that law denied her constitutional right to privacy
- c. “the state does have an important and legitimate interest in preserving and protecting the health of the pregnant woman . . . [and] it has still another important and legitimate interest in protecting the potentiality of human life. These interests are separate and distinct. Each grows in substantiality as the woman approaches term and, at a point during pregnancy, each becomes ‘compelling’” (Justice Blackmun)

8. Freedom of Information Act (amended 1986)

- a. spells out the situations and conditions pertaining to the right of the U.S. taxpayer to obtain information he / she has paid for from agencies within the Federal Government
- b. potential for conflicting interests in such situations, if information about taxpayer A is released to taxpayer B

9. essential aspect in designing a surveillance program

- a. assurance to the persons (agencies) who report and those being reported upon that the privacy rights of the persons whose health information is of interest will not be violated
- b. many states provide protection of individual rights
- c. conflict between the right to privacy and the need to know represents an area that must be monitored by surveillance managers
- d. example: toxic-shock syndrome (1970s-1980s)

- 1) attorneys representing tampon manufacturer wanted the data and names of women with toxic-shock syndrome
- 2) Court ruled that confidentiality will be protected by the federal government
- 3) position will continue to be challenged

D. Right of access

1. right of access position formed by opinion that if the taxpayers support the gathering of information, they have a right to that information
2. reasonable-man position
 - a. maintains that a person has a right to any information about him/herself
 - b. giving information to an individual can have the effect of providing information that assigns liability to another person or organization in the data set
3. third-party inquirers
 - a. individuals call for information on a need-to-know basis
 - b. Congress
 - c. attorneys
 - d. special-interest groups
 - e. news media
4. making a data set public
 - a. there is no legal precedent
 - b. once the first paper has been published about a data set, it is prudent to place that data set in the public domain if there is a reasonable expectation of its further use
 - c. can create the risk of extra work and having others preempt publication

- d. obviates accusations about willful withholding of information or the danger that forced release of data before they are properly prepared for public use will allow some subjects to be identified

E. Product liability

1. is not unusual for investigations to show that a product is contaminated, that a machine was used incorrectly, or that tampering has occurred
2. difficult to deal with a situation in which an well-designed product can lead to a life-threatening illness
3. example: toxic-shock syndrome
 - a. manufacturers went through class grief reaction
 - b. denial, anger, depression, acceptance, resolution
4. surveillance programs should be flawless and all information reported should be unassailable
5. practitioners must be prepared to deal with issues on a mixture of levels
 - a. public health
 - b. legal
 - c. ethical
 - d. sociocultural
 - e. emotional

F. Litigation demands

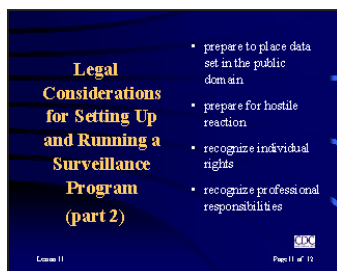
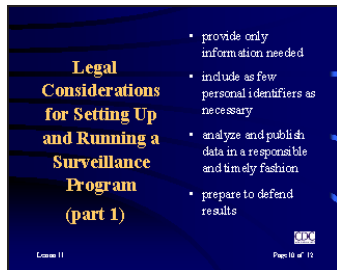
1. to what extent is an agency responsible for providing its staff to testify in litigation regarding surveillance findings

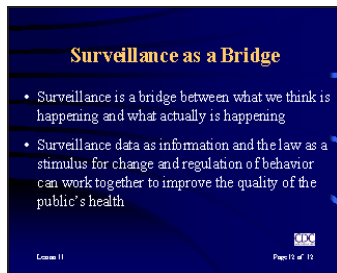
2. it is not responsible behavior to refuse to provide expert testimony as it is needed
3. in situations in which there are massive numbers of suits being conducted over a period of several years, the scientific resources of an agency could be expended on time in court and no time spent on science
4. there is no easy answer but issue must be faced when planning surveillance activities

IV. Conclusion

A. Considerations for setting up and running a surveillance program

1. plan and design surveillance systems so that they are most likely to provide all the information and only the information actually needed
2. include as few personal identifiers as necessary
3. analyze and publish data in a responsible and timely fashion
4. be prepared to stand behind the results
(and hope your agency will stand behind you)
5. be prepared to place each data set in the public domain as soon as the first results are published
6. if the findings are revolutionary, be prepared for a hostile reaction rather than a medal
7. individuals have rights
8. public health practitioner has responsibilities





B. Surveillance as a bridge

1. serves as a bridge between what we think is happening and what is actually happening
2. as a bridge, it is one of the most valuable tools of the public health practitioner
3. when surveillance data is used as an information source, and the law is used as a stimulus for change and the regulation of behavior, these two areas can work in concert to improve the quality of the public's health